

New Zealand Adolescent and Young Adult Cancer

# ACTION PLAN

2020 TO 2025

MAHERE TAUTAPA MATE  
PUKUPUKU TAIOHI



Our commitment to improving outcomes  
and achieving equity for young people  
diagnosed with cancer in Aotearoa

**AYA** CANCER  
NETWORK  
AOTEAROA  
ADVANCING CANCER CARE FOR 12-24 YEAR OLDS

**Hapaitia te ara tika pūmau ai te  
rangtiratanga mo ngā uri whakatipu.**

Foster the pathway of knowledge to strength,  
independence and growth for future generations.

Whakatauki gifted by Jayden Pattison  
(AYA Cancer Consumer Advisory Group Member)

# THE VOICE OF THE YOUNG PERSON TE REO O TE TAIOHI



Kia ora koutou,

**My name is Justin and I'm from a little place in the far north called Pawarenga Te Uri O Tai. I just recently married my high school sweet heart and I am a lucky father of three beautiful kids. I'm a mad keen hunter, fisherman, kai gatherer - basically anything to do with outside I'm all in. I love being outdoors and taking my family and showing them that here in Aotearoa we are so blessed to have everything we need. All you got to do is go out and get it.**

My journey with cancer began late 2013 I had just moved myself and my family to Melbourne where I started working and trying to set a life up for us. Little did we realise how much our lives would change over the coming months. In the beginning of what was the start of a long and tough battle for me I came down with flu like symptoms, high fever, night shivers, etc. Not realising how much trouble I was actually in I brushed it off as a simple flu ignoring the fact that I had also developed two lumps on my thigh. After I finally saw a doctor I was admitted to hospital where I would stay for the next 6 months. This stay resulted in multiple surgeries, an induced coma, a period of time on dialysis and need to learn to walk again. For my family the outcome of what I had been through seemed like the hardest time in their lives but it was only the beginning - it felt like blow after blow and what made it worse was that I was still experiencing my symptoms that I started off with.

## **Nothing seemed to be getting better.**

I had the top teams of specialists working hard to try and figure out what was wrong and after multiple tests it was found that I had a rare form of lymphoma that required aggressive chemo therapy right away. Finding this out I then started my treatments in Australia but unsure of my future ahead I decided that it was best for me and my family to move back home to New Zealand and carry on the rest of my treatments here on the understanding that it would be easier to get support for myself and family. After landing back home and speaking to the specialist and coming up with a plan to battle my cancer, I began to try and find the support I felt I needed.

Finding the right support was tough; there are so many barriers that existed for us as low income earners. It was hard I basically had to beg the system to get what was actually there unbeknown to me.

My whānau were too broke to visit me and my wife and I never got to see our kids. She had to balance caring for me and looking after them. I was relying on charities to donate me petrol vouchers to get me to appointments. Some weeks I struggled in order to get help with food to get me and my family through. It was pretty crazy. Being in hospital left me feeling lonely and by myself, I would even hold off coming in when I knew I should as I really didn't want to stay there.

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*My journey has been rough and is still far from over but having gone through what I have, I realised that I wanted to help future young people who have and still are going through their cancer journey to get through it a little easier than I did.*

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One way I can do this is by highlighting the reality of what it is really like for some of us going through cancer treatment as a young adult here in Aotearoa. I am now the co-chair of the AYA Cancer Advisory Group and a member of the AYA Cancer Network Governance Group. I believe this plan that the advisory group have helped create with the AYA Cancer Network captures our voices by thinking of all of the things needed to make sure all young people receive the support they deserve no matter who they are or where they come from.

I ask that you get in behind this plan and make the journey of future young people easier than mine was.

Thank you,  
Justin



## Background Tuarongo

**On average 190 young people are diagnosed with cancer every year in New Zealand<sup>(1)</sup>. While this makes up less than 1% of the total population diagnosed, for young people it is the leading cause of disease-related death<sup>(2)</sup>.**

Young people tend to sit on the periphery of cancer care, often falling into a “no-man’s land” between paediatric and adult cancer services. Adolescents and young adults (AYAs) have distinct and often unmet needs and the spectrum of AYA cancers that present in this age group differ to child and adult cancers, as do tumour and host biology factors. In addition, the psychosocial care needs of AYAs with cancer tend to be broader in scope and intensity than children or older adults due to the many emotional, developmental and social changes occurring during this stage<sup>(3)</sup>.

To determine and direct improvements in cancer services for young people the Ministry of Health announced additional funding to establish the AYA Cancer Network Aotearoa in 2013. The Network provides strategic direction and clinical leadership of AYA cancer care in New Zealand and is contracted directly to Te Aho o Te Kahu (the Cancer Control Agency) to undertake this role. The Network is a membership organisation that connects hands-on

health professionals and support providers from many disciplines and organisations. The aim of the Network is to find new and innovative ways of delivering care to all AYAs diagnosed with cancer and ultimately, to improve outcomes.

Over the last decade, New Zealand has seen improved survival rates for AYAs, as shown on the following page, through a number of complex and intertwining factors. While this is significant and reassuring, we must not become complacent. Still existing are unacceptable disparities, inequities and variation in cancer care outcomes for young New Zealanders, particularly for Māori. To continue to support and guide on-going improvements, the AYA Cancer Network has developed this national plan for the next five year period.

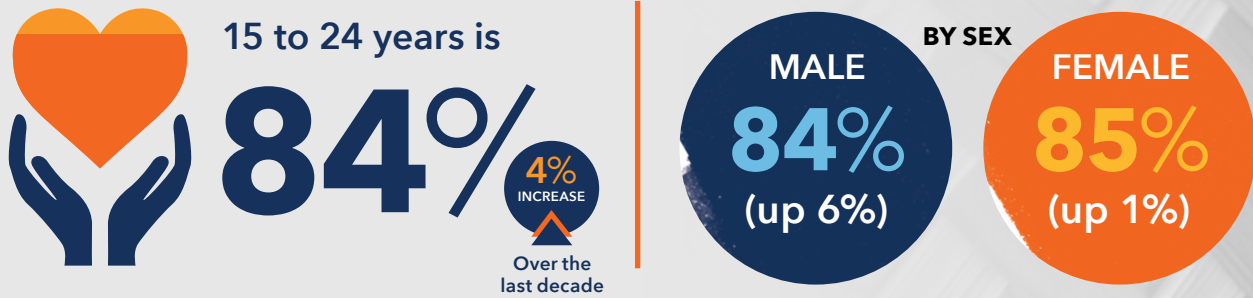
### AYA CANCER NETWORK AOTEAROA

Connecting professionals, patients, carers and other stakeholders with an interest in improving AYA cancer outcomes

Leading collaboration for service development, across the continuum of cancer care for AYA

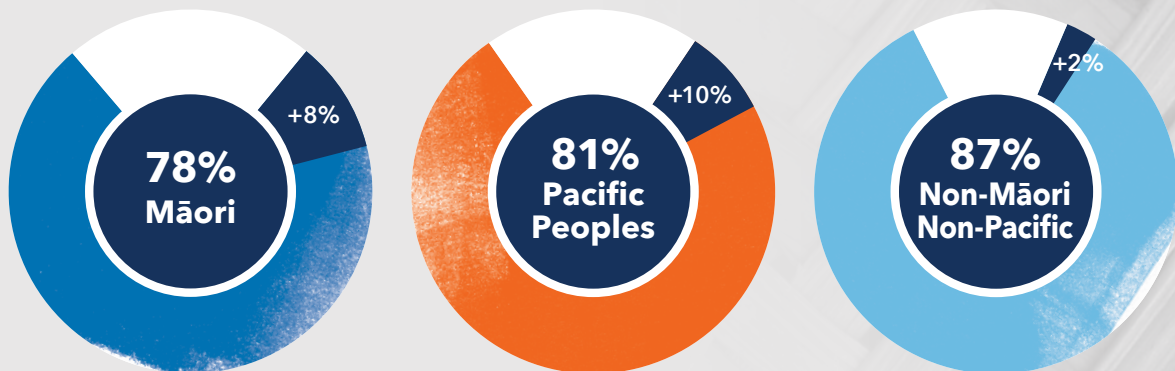
# 5 year cancer survival improvements in the past decade (2000 - 2009 versus 2008 - 2017) <sup>(1)</sup>

## AYA cancer survival rate in New Zealand



## Prioritised Ethnicity

The percentages in the middle are survival rates for 2008 to 2017. The smaller percentages are how much survival rates have improved over the last decade. <sup>(1)</sup>



## Age

The dotted lines represent Australia (2010 to 2014) -  
15-19 years - 87%  
20-24 years - 90%

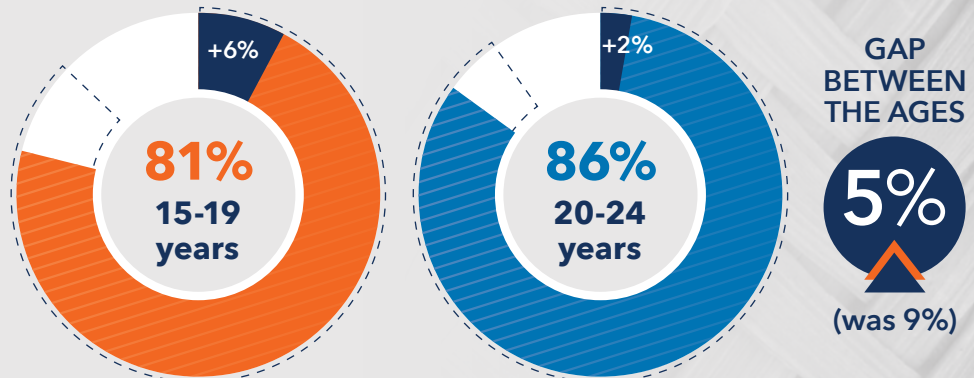




Photo credit: Trefor Ward / treforward.com

# New Zealand Adolescent and Young Adult Cancer Action Plan 2020 to 2025 Mahere Tautapa Mate Pukupuku Taiohi 2020 - 2025

The New Zealand AYA Cancer action plan is aimed at both government and non-government organisations involved in programme development and funding, planning, policy and delivery of AYA cancer support services.

It is founded on an understanding of the core elements of effective AYA cancer care and service delivery detailed within the 2016 AYA Cancer Network Aotearoa Standards of Care (SOC) <sup>(3)</sup>. It is recommended that this plan is therefore viewed in partnership with the SOC, a copy of which can be downloaded via <https://ayacancernetwork.org.nz/standardsofcare>.

The plan was developed in response to the insight provided and obtained by the Network since its establishment. This includes an extensive review of literature and reports relevant to AYA cancer care, a number of research projects, a self-review process undertaken by all 20 District Health Boards (DHBs) specific to AYA cancer, and a national patient experience survey which 200 young people with cancer across the country completed <sup>(4)</sup>. It is therefore a collective representation of significant consumer and provider input.

Within the plan, this input has been translated into specific national priorities with complementary actions to attain success and achieve optimal and equitable cancer care delivery for all young people in Aotearoa. It is envisaged that experts in the priority areas will lead small working/project groups, to guide the implementation of the associated actions. There is variation in the detail and specificity of these actions as several priority areas have already received attention through work undertaken in previous network annual programmes. There is also subsequent variation in which each action will be complete with many representing short to medium term aspirations (two to three years) and several being longer term objectives (four to five years).

The AYA Cancer Network Aotearoa will oversee and monitor the implementation of this plan, while also adapting the plan in response to any emerging and developing priorities as they may arise.

The plan is aligned to and fits within the overarching principles of the New Zealand Cancer Action Plan 2019 -2029, and is consistent with the goal of achieving cancer survival equity by 2030.

### **Action plan user guide:**

All text within the circles on each priority page, that does not have a reference number, is a finding from the recent patient experience survey undertaken by the Network titled 'Whakarongo mai: Listen to me'<sup>(4)</sup>. If taken from another Network publication or report the supporting reference is noted.

The priorities are also supported through quote(s) from a young person, their whānau or an AYA clinician, captured by the Network over recent years. These quotes have been left verbatim to preserve authenticity.

**GOAL:** By 2025 all young New Zealanders diagnosed with cancer will have equitable access to high quality medical and supportive care regardless of where they live, their age or ethnicity.



## Our promise to achieving inclusiveness and equity in outcome

# Kō tā mātou ōhākī ka taurite ngā whiwhinga ki te katoa

**Within New Zealand, great diversity exists in the characteristics, identity and backgrounds of young people.**

This includes gender, ethnicity, migrant status, socio-economic status, sexual orientation, geographical location, disability, religious affiliation and whānau structure. For some young people their diversity can result in inequitable access to responsive and appropriate resourcing and opportunities needed to thrive. These struggles can also compound when young people have multiple, intersecting diverse identities<sup>(5)</sup>.

Evidence of such inequity is in the current survival rates of Māori rangatahi. While the gap between Māori and non-Māori has lessened over the last decade, it has not yet closed with a 9% difference in survival between Māori and non-Māori/non-Pacific young people<sup>(1)</sup>. This disparity is unacceptable.

Consequently, as with the pieces of work that have founded this action plan, the implementation of each action will be guided by the recommendations of sector and cultural experts and young people/whānau. Specific equity tools, such as the Health Equity Assessment Tool (HEAT), will be utilised to examine the potential for initiatives/interventions to be more inclusive and responsive to meeting the diverse needs of young people in Aotearoa. While survival is one of the key outcomes considered within this action plan, many other important measures of cancer care equity are to be prioritised. These measures include fertility, psychological health, vocational achievement and financial independence.



# Priorities Ngā Arotaunga

Following the extensive work undertaken by the Network, eighteen priorities have been identified for the national action plan with complementary actions to attain success in the goal of achieving optimal and equitable AYA cancer care delivery. These are:

1	<b>Reducing unwarranted variation in AYA cancer care</b> Kia heke iho te pokakē ki waenga o te manaaki hunga mate pukupuku AYA	10
2	<b>Achieving equity in outcome by levelled psychosocial care provision, 'the stepped care model approach'</b> Kia taurite ngā whiwhinga mā te raupapa manaaki hinengaro arā ki te taura manaaki mā te arapiki	11
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15	<b>Traditional and complementary therapy</b> Haumanu inamata me te hāngai pū	27
16	<b>Holistic wellbeing</b> Oranga torowhānui	28
17	<b>Increased collaborative AYA cancer specific research</b> Rangahau hāngai ki te mate Pukupuku AYA pikinga ngātahi	29
18	<b>Age appropriate treatment environments</b> Ngā wāhi pikinga o te ora kia ōrite ki ngā tau	30

It is recognised that throughout the country a number of services providers are already well advanced in delivering several actions outlined in the plan due to multiple influencing factors.

It is envisaged that these providers will support similar advancement in other services through shared knowledge and resource while providing an exemplar of leadership as to how to promote similar practice across the country.

# Reducing unwarranted variation in AYA cancer care

## Kia heke iho te pokakē ki waenga o te manaaki hunga mate pukupuku AYA

**No nationally agreed pathway of care exists for AYAs with cancer in New Zealand.**

Consequently, there is duplication and variance in resourcing, service delivery, cancer management and patient experience across the care continuum. This is dependent on where a young person lives, their ethnicity, the service they are under (i.e. paediatrics or adults) and their age. This is undesirable, unacceptable and a potential contributor to the existing variability in outcomes for AYA patients.

An example of such variation can be seen in clinical trial enrolment. Between June 2017 and June 2018 27 AYAs were diagnosed with Hodgkin Lymphoma, and while the spread of these cases across New Zealand was evenly distributed, of the five AYAs enrolled on a clinical trial during this period, four were from Auckland and one was from Canterbury <sup>(6)</sup>.

Young people in smaller centres are 5.85 times less likely to have had a conversation on the impact of treatment on fertility

Young people in paediatric environments were 2.48 times more likely to report always receiving enough pain relief and/or support for uncomfortable and painful procedures than those in adult environments

*‘Where services were identified as operating effectively, this was often clinician dependent rather than a system drive.’*

AYA clinician

*‘I was surprised to hear from other members of our group that they were not offered the same supports as I was... Honestly I’m not sure how they got through their treatment without the support I received.’*

AYA advisory group member

### ACTION STEPS

#### Reducing unwarranted variation in AYA cancer care

Develop a national AYA cancer pathway of care that promotes localised cancer care delivery where possible, with a centralised decision-making and monitoring process. This is to be complemented with a supporting business case for submission to Te Aho o Te Kahu (Cancer Control Agency).

Collaborate with tumour and clinical special interest groups to agree on nationally approved protocols and management for common AYA cancers.

Develop a national guideline for optimal procedural analgesia and sedation for AYA cancer patients.

Development of AYA specific resources, templates, checklists, and tools for both providers and young people to support consistency of care. Examples include initial assessment tools, fertility preservation checklists, and education packages. These are to be made available through the AYA Cancer Network website.

## Achieving equity in outcome by levelled psychosocial care provision, 'the stepped care model approach' Kia taurite ngā whiwhinga mā te raupapa manaaki hinengaro arā ki te taurira manaaki mā te arapiki.

There are situations and psychosocial risk factors that based on evidence result in young people struggling to engage and access existing structures and services<sup>(3)</sup>.

This can leave them disadvantaged and vulnerable to negative survival and quality of life outcomes. Too often our most vulnerable young people are not identified and prioritised in the existing system. It is vital that this is rectified and that services become more responsive, innovative and proactive to the needs of the most disadvantaged.

Māori rangatahi experience financial stressors (transport difficulties, prescription affordability, parking costs, no phone or insufficient credit on phone, benefit being cut due to expired medical certificate) more than non-Māori

*'I held off coming in with a fever a few times, but if it didn't get better, or I felt maybe it's not going to go away I would start getting a little bit worried and then come in. If parking wasn't so expensive, and fuel wasn't so expensive I would have been able to come in earlier.'*

AYA

### ACTION STEPS

#### Achieving equity in outcome by levelled psychosocial care provision

Develop a national AYA cancer tiered framework for the guidance and delivery of psychosocial care. This will involve collaboration with relevant organisations and agencies (health services, non-governmental organisations, community agencies and Māori health providers) to establish national consensus on the proposed interventions and intensity of support to be delivered at each tier.

In partnership with stakeholders explore the development of new and innovative roles that build resilience of young people and their whānau and aim to overcome barriers and challenges in accessing traditional health care services.

Development of:

- a standardised psychosocial assessment tool/process
- a risk identification tool
- a psychosocial care plan/template
- resources and inventive solutions to support addressing the practical and financial difficulties AYAs experience.

Ensure the voice of young people and their needs are represented in the existing work been undertaken by Te Aho o Te Kahu (the Cancer Control Agency) in advocating for improved access to travel and accommodation supports through the National Travel Assistance Scheme.

*'I was left in a very vulnerable living situation. I had been working and flatting ever since I left high school and my foundation of a family was held down by my friends... I was constantly in and out of hospital, living there more than my \$150 a week flat. When my big chemo treatment was to commence it was a struggle to find care and a roof to live under.'*

AYA

## Access to an AYA cancer keyworker Tomonga ki tētahi pou āwhina mate pukupuku AYA

One of the overwhelming findings from the background work undertaken to guide the action plan was how highly valued the AYA regional Keyworker roles were by both young people and cancer care providers.

The role provides specialised cancer care coordination and oversight for the AYA age group and access to an AYA Keyworker has been identified as a key protective factor for a young person on treatment. Positive outcomes include greater treatment adherence, a reduction in did-not-attend numbers for outpatient clinic appointments; better psychosocial health and wellbeing among AYA patients and whānau; improved timeliness of access to services, supports and treatments; and improved oversight and continuity of care <sup>(7)</sup>.

AYA Keyworkers predominantly work autonomously and very much in isolation across multiple services and DHBs. The ability for the Keyworker to service their whole region is heavily influenced by resource and location.

A recent comparison of each AYA Keyworker's 2018 patient dataset against the 'gold-standard' New Zealand Cancer Registry (NZCR) identified that one third of AYAs diagnosed with cancer were not known to the AYA Keyworkers <sup>(8)</sup>

### ACTION STEPS

#### Ensuring the on-going effectiveness and sustainability of the AYA cancer Keyworker model

Clarification of the roles and responsibilities of AYA Keyworkers and AYA champions with the purpose of improving national consistency, and where necessary advocate for adequate resourcing.

Establish processes to improve referral rates and timeliness of referrals to regional AYA cancer Keyworkers.

Continue to support a process where measures to address operational priorities identified by the AYA Keyworker working group is implemented.

Explore strategies to reduce the isolation and vulnerability of the AYA cancer Keyworker service and roles.

*'I was lucky to have the care of an incredible AYA Keyworker who made it more than her personal mission to ensure that I was well looked after even if it meant being in hospital till I had a guaranteed safe haven to go home to... She stepped in and took action with my day to day stability and assisting me with my job, government support and finally passing me over to my whangai family.'*

AYA

*'The physical distance between centres can provide significant constraint on the frequency to meet with AYAs as well as promoting AYA cancer service visibility within these centres.'*

AYA Clinician

## Data and monitoring to drive change

### Raraunga me te aroturuki ki te akiaki huarahi

Currently in New Zealand, there is an absence of consistent, uniformed and accurate AYA data collection.

Without this, effective monitoring of cancer service delivery cannot occur. Subsequently, investigation as to the feasibility of a minimum national AYA cancer data set or registry is a priority. A New Zealand AYA cancer data set would support the planning, monitoring and quality improvement of AYA cancer health services.

While the AYA cancer incidence and survival in New Zealand 2008-2017 report has provided invaluable insight, it is currently beyond the scope of analysis to examine many of the factors known to influence AYA patient outcomes, such as potential diagnostic delays, referral pathways, enrolment in clinical trials, and access to appropriate support services. Obtaining such data in the future – collected and analysed as close to real-time as possible – will be vital to address the identified disparities, and to drive improvements for current AYA patients<sup>(1)</sup>

#### ACTION STEPS

##### A national approach to AYA cancer data collection and monitoring is adopted

Establish the requirements and investigate the feasibility of a national AYA cancer data set to support clinical case management, service planning, clinical performance monitoring and research.

Create mechanisms to monitor and evaluate the delivery of AYA cancer care across the continuum through:

- capturing the patient experience
- developing a set of AYA cancer quality performance indicators
- continuation of the online AYA cancer self-review process
- undertaking national AYA cancer incidence and survival analysis every 5 years

Develop an equity-focused structure which at a minimum covers collecting, analysing and reporting ethnicity data.

Ensure timely dissemination of AYA cancer data and findings that drives quality improvement.

*‘Data for AYA in NZ is lacking, is inconsistently collected, and is not visible to providers.’*

AYA Clinician

*‘I want to know the treatment I get in New Zealand is as good as anywhere else in the world.’*

AYA



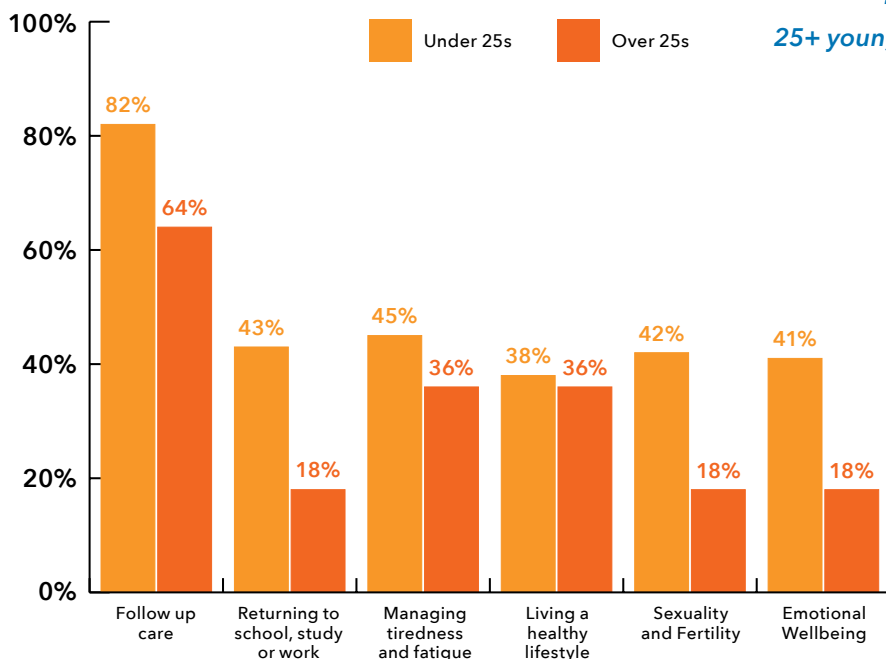
## Redefining the age range for AYA He arotake i te rāngai kaumātua mō ngā hunga AYA

The AYA Cancer Network Aotearoa currently defines the AYA age range as 12 to 24 years. There is an increasing desire from stakeholders for the Network to consider extending the AYA age range to include the 25 to 29 year-old cohort.

Approximately 160 young people aged 25-29 are diagnosed with cancer each year. It is known that this group faces many of the same challenges experienced by AYAs with regard to outcomes, developmental needs, treatment effectiveness and tolerance, adherence and early death <sup>(9)</sup>.

Across all areas of end of treatment and follow-up care, those aged 25 to 29 years fared less well than those under 25 years

Access to after-treatment support that was helpful (by AYA compared to older young adults) <sup>(4)</sup>



### ACTION STEPS

#### Redefining the AYA age by extending the upper range to 29 years

Complete a national analysis of resource and service delivery impact if the AYA age range was extended to 29 years. This includes identifying the benefits and risks associated with an age extension and with this, possible delivery models.

Collaborate with the National Child Cancer Network (NCCN) to explore a model of care that might best meet the needs of the 12 to 14 year old age group.

Dependent on the above actions, present a national proposal/business case to Te Aho o Te Kahu (Cancer Control Agency) for endorsement to redefine the AYA age range.

*'I think there needs to be more support networking for young people, I was never offered an opportunity to meet other young people or have support groups that were under age of 30. Most of the support offered did not apply to my situation and were generic support groups full of older people.'*

25+ young adult

*'What support is there for people over 24 years?'*

25+ young adult

There is also discussion pertaining to the on-going inclusion of the 12 to 14 year age group to the same extent as the remaining AYA cohort. This is due to evidence that prior to and since the establishment of the AYA Cancer Network no disparities have existed for this group <sup>(10)</sup>. Further to this, the majority of 12 to 14 year olds have paediatric cancer and receive care under child cancer services, which already have comprehensive psychosocial wrap around care. In the essence of equity and consideration of resource implications, the question must therefore be asked - should AYA cancer services continue to prioritise and resource this age group?

## Clinical trial participation

### Urunga mātautau haumanu

Gains in survival rates over the past 20 years have not been as marked in the AYA cancer population compared to the paediatric and adult cancer populations.

In part this is regularly attributed to a lower rate of clinical trial enrolment. In New Zealand enrolment onto clinical trials for the paediatric population is approximately 30 to 50%, significantly higher than the AYA population aged 15 to 24 years at approximately 5%, this half of the AYA Australian trial enrolment figure of 10.3%<sup>(6)</sup>.

It is well documented in the cancer care sector that infrastructure barriers, significant DHB resource requirements, and the need for extensive logistical planning contribute to a lack of clinical trial participation prioritisation. When you combine this with the small AYA population and often rare cancer types, it becomes even more challenging to achieve success; that is the establishment, provision of and patient enrolment on a clinical trial. Where trials are open in New Zealand there is inequity in access, often dependent on where a young person resides and the age at which they are diagnosed.

While overcoming these barriers may seem like a formidable task, it has and continues to be achieved by New Zealand's Child Cancer Service. The fact that paediatric and adult services have such vast differences in clinical trial resourcing further highlights structural inequity.

In 2019 the New Zealand Children's Cancer Registry recorded a total of 30 enrolments in 11 open international clinical trials and a further 75 registrations in eight different non-therapeutic studies, such as tumour biology studies, international registries, and fertility preservation research<sup>(8)</sup>

#### ACTION STEPS

##### Improving access to Clinical Trial Participation

Endorsement is to be sought from Te Aho o Te Kahu to ensure phase two and three clinical trials are considered optimal standard of care for all AYAs in New Zealand to facilitate equitable access. If achieved the following steps will need to then be progressed.

- Shared care service agreements will be put into operation to ensure AYAs can travel within New Zealand to an eligible trial. These will outline financial, resource and clinical responsibilities and implications.
- Supportive care guidelines and communication pathways are to be developed and implemented.
- Financial and logistical barriers for AYA and their whānau are identified and plans to address these barriers developed.
- Workforce training requirements are identified and on-going professional development is facilitated for shared care delivery.

Opportunities are explored to increase availability of clinical trials for the AYA age group including collaboration with Australian health care services.

*'So because I don't live in Christchurch or Auckland I miss out on being on a trial that could increase my survival?'*

19 year old AYA

*'For AYA, solutions are required that improve the interface and cross-flow between adult and paediatric centres, ideally with provision for specialist clinical trial care hubs.'*

AYA Clinician



## Understanding the current gaps in survivorship within the AYA cancer population

### Kia mārama ki ngā whārua mō te putanga ki te ora mō te rāngai AYA mate pukupuku

The AYA Cancer Incidence and Survival analysis for the 2008-2017 period provides strong evidence that the efforts of the past decade to close the gap for our young people with cancer are working. Survival rates are improving, notably for our adolescents, males, and Māori and Pacific AYA. But there is a great deal of work still to be done. Differences and inequities in outcome still remain for certain ethnic, disease specific and age groups<sup>(1)</sup>.

The relationship between the geographical location in which a young person lives and survival outcomes were explored in the recent incidence and survival analysis for the first time in New Zealand. Five-year survival across the six AYA cancer centres ranged between 77 and 91%. Notably, the highest survival rates were for those AYA living in the least deprived areas, in major cities, and within 20 kilometres of their AYA cancer centre<sup>(1)</sup>.

#### ACTION STEPS

Undertake targeted research to provide greater understanding of current gaps in survivorship for specific groups within the AYA cancer population

Undertake further work to identify potential contributors to the survival disparities within some AYA cancer groups, including Maori and Pacific AYA, AYA diagnosed with central-nervous system (CNS) tumours and regional differences.

Advocate as appropriate to Te Aho o te Kahu (the Cancer Control Agency) with supporting evidence as to how the Agency can work with the AYA Cancer Network to deliver a targeted response to address these survival disparities

While we have excellent survival rates for many common AYA cancers, five-year survival remains less than 70% for AYA diagnosed with central nervous system tumours (59%), bone tumours (62%) and soft tissue sarcomas (69%). And, although the gap has narrowed, our overall cancer survival rates are still 5% below what has been achieved for AYA in Australia<sup>(1)</sup>

*‘Over half the young people in my age group with bone cancer [15 to 19 years] don’t survive their disease. My close friend Sally didn’t. However if she had lived in the US where I was heading to travel on a scholarship before being diagnosed she would have a better shot at survival, in fact 17% more for bone cancer. I want you to know we deserve better.’*

AYA (2008)

## Caring, supporting and involving whānau, partners and the community

### Atawhai, tautoko me te uru ngātahi o ngā whānau, ngā hoa pūmau me te hāpori

Strong, healthy whānau relationships are essential to a young person's psychological and physical health<sup>(3)</sup>.

Individuals and community groups who are influential in a young person's life should be identified and engaged proactively in their health care. Young people have also frequently conveyed to the Network that their whānau often do not receive adequate emotional, practical and financial support. This is not only distressing; it can also place an additional burden on the young person.

A third  
of young people  
identified not always  
having whānau or a  
significant person with  
them when important  
information was  
given

*'My family was with me for 6 plus hours before they went back to the motel to have a shower and get some food, and it was at that time the doc came in and told me I had cancer.'*

AYA

*'When we were in the interviews/meetings my mum didn't really understand the big words so I had to explain it all when we left.'*

Samoan AYA

New Zealand represents a diverse range of ethnicities and cultures and within this there are variations in people's belief systems, values, whānau structures and practices. To work effectively with such a diverse population, services and providers must be culturally responsive and committed to meeting the needs of all.

#### ACTION STEPS

##### Including and supporting Whānau, Partners and the Community

In collaboration with whānau, partners, communities and the broader social networks of AYAs, seek feedback on existing services and supports currently available to them. Collaborate to identify areas for improvement and implementation strategies. There will be a commitment to partner with Māori to ensure equitable and culturally responsive initiatives are developed and implemented.

Develop informational resources to support whānau when a young person is diagnosed with cancer.

Collaborate with the wider AYA cancer sector i.e., non-governmental organisations, to explore opportunities to improve responsiveness to the cultural, practical and emotional needs of AYAs, their whānau and communities.

Establish guidelines and tools for health providers to ensure whānau-centred involvement in the care young people receive and the decisions they make.

18% of  
Māori AYAs did  
not receive  
cultural support  
but would have  
liked to

*'The hospital sent the Samoan Cultural Liaison person to support my mum because I have a Samoan last name, but my mum is Māori... so that didn't work very well. People always make assumptions.'*

AYA

## Workforce development

### Whanake rōpū mahi

It is not uncommon for health professionals working with AYA patients to report a lack of skills to address both the health and psychosocial needs of this particular age group<sup>(3)</sup>.

The best care for AYA cancer patients is provided by health professionals who have been specifically trained to care for them.

*'Need to make sure this is a whole service - this is not just about the keyworker role. They can't do everything so other staff need to be trained up.'*

AYA Clinician

*'It's great having a team that you can talk to and get to know with more information conveyed than just treatment. Staff make these places.'*

AYA

A consistent preference voiced by rangatahi and Pacific young people at Network hosted workshops and hui's, is to be cared for by someone identifying with a similar culture. However not unique to AYA cancer care is the shortage of Māori and Pacific health care professionals to provide appropriate care for these priority populations. Whilst someone of a similar culture is the ideal, young people also place emphasis on health professionals taking the time to get to know them and their culture; this goes a long way towards building connection both for their whānau and themselves.

*'If we had a male doctor like a Samoan doctor someone that I could see myself relating to then that would be a big plus and would also really help my Mum.'*

AYA

#### ACTION STEPS

**The AYA cancer workforce is trained to deliver developmentally appropriate and culturally responsive care**

The development and implementation of a culturally responsive national AYA cancer workforce knowledge and skills framework.

Determine, explore and support the development of a range of training, education and learning opportunities for those in or interested in AYA cancer care. Delivery possibilities include multiple platforms and environments such as on-site training, post-graduate qualifications, online training, fellowships and mentorship.

Use collaborative and proactive measures to strengthen the Māori, Pacific and Asian participation in the AYA cancer workforce.

*'Speaking the Māori language is an important thing to me... it coincides with pronunciation of my name. Because I'm named after one of my ancestors and when I get a health professional who takes the time to actually say my name correctly that shows that they care not only for me but for my whole family and my culture... yeah they care about my culture.'*

AYA Clinician



## Fertility preservation Tiakanga matahau

Fertility related distress is common in AYA cancer patients both during their treatment and beyond it<sup>(3)</sup>.

Many describe the prospect of therapy-related infertility to be as distressing as the cancer diagnosis itself<sup>(3)</sup>. As increasing numbers of young people survive their cancer, the topic of fertility has become ever more relevant and in need of attention.

Only **35%**  
of all young people  
successfully preserved  
their fertility  
prior to starting  
treatment

*‘It was mid-May when I was diagnosed and six weeks later it was a day before chemo when they first told me about fertility and that I was not going to be able to have kids... I was quite annoyed that it was six weeks later... they knew I was young.’*

AYA

*‘To this day that news haunts me. Growing up all I thought about was trying to build a life, a foundation for my kids and generation to come. Though I wasn’t planning it then at 19 it sure was in my future plan.’*

AYA

### ACTION STEPS

#### Fertility preservation will be prioritised and addressed with young people

A fertility preservation working group will be re-established and tasked with reviewing and updating the 2014 New Zealand fertility preservation guidelines/pathways of care.

Develop age appropriate, LGBTQI+ inclusive and culturally responsive fertility preservation tools, templates, checklists and promotional resourcing to support clinicians in addressing the fertility preservation needs of young people.

Advocate and explore solutions for equity of access to fertility consultation and preservation for young people regardless of where they reside, their age or stage in the cancer care continuum.

## Early identification

### Tautuhinga moata

When compared to children and older adults, AYA cancer patients are at a greater risk of diagnostic delay.

This is due to a complex mix of disease-related, patient-related, and healthcare-related factors. These include but are not limited to: reduced access to care; low levels of health literacy and cancer awareness; vague symptoms which AYAs and primary healthcare professionals can attribute to AYA age and stage; and the rarity of AYA cancer (11-14).

A recent New Zealand study found that there is a significant self-identified knowledge gap for primary healthcare providers related to pre-diagnosis (symptoms and pathways) of AYA cancer. It was also found that 54% of primary healthcare providers reported that consultation time impacted their ability to explore vague symptoms 'always' or 'most of the time'; and 67% cited time as the biggest barrier to participating in AYA cancer education <sup>(15)</sup>.

**35%**  
of young people  
visited their  
GP/health professional  
**more than three times**  
**before being referred**  
to a specialist/  
hospital

*'I spent a bit more than six months visiting the GP over a dozen times before I was finally referred for an ultrasound and then diagnosed.'*

AYA

*'I don't feel that the [doctor] that I saw took me seriously and I feel that I could have been diagnosed much earlier if he had listened properly.'*

AYA

#### ACTION STEPS

##### Early symptoms of cancer will be recognised by health care providers

Establish a national five year prospective study to investigate timelines to diagnosis with the potential associations to mortality and reoccurrence of disease. As part of this a national analysis will be undertaken to highlight areas where targeted interventions are required.

Exploration of a variety of national educational, training and communication initiatives targeting youth health and primary care providers, to improve awareness of AYA cancer risk and referral practices.

## Survivorship Toioranga

Following completion of treatment, it is well known that young people face numerous challenges and stressors.

For example, cancer survivors in the AYA age group are at heightened risk of psychological late-effects including posttraumatic stress, depression and anxiety<sup>(3)</sup>. Psychosocial issues AYAs face in survivorship include fear of disease reoccurrence, difficulties with the formation and maintenance of friendships/intimate relationships, forgetfulness and inattention, sexual concerns and fertility-related distress<sup>(3)</sup>.

Young peoples' after-treatment needs for physical, social and emotional support were not met half to one third of the time

*'The hospital should be having more things in place to assist us in our recovery such as immediate follow-up classes or sessions for diet, fitness, mental health etc. because if anything recovery is the hardest part is this whole journey.'*

AYA

Communicated strongly in the review by stakeholders are the gaps in service provision and support for the survivorship period and once again variation depending on whether the AYA is treated as a paediatric or adult patient. Young people report that the care received into survivorship often does not meet their needs to the level experienced while on treatment<sup>(4)</sup>.

### ACTION STEPS

**AYA will have access to a structured follow-up plan that focuses on the multifaceted issues of survivorship**

Support the implementation of a national formal end of treatment summary/care plan to be undertaken for all young people on completion of treatment.

Collaboration with tumour and clinical special interest groups to agree on nationally approved surveillance/follow-up guidelines for common AYA cancers.

Advocate for increased resource provision to effectively implement post-treatment cancer surveillance guidelines.

Through collaboration across the AYA cancer sector, pilot and evaluate a comprehensive AYA reintegration survivorship programme focusing on topics such as: healthy lifestyle, fatigue management, increasing exercise tolerance, emotional wellbeing, self-management, return to work/study and re-establishment of social networks.

Only 22% of young people received a detailed written end-of-treatment summary on completion of treatment

*'I would have loved follow-up plans to be given in written form... Since finishing treatment I have only talked with and seen my surgeon who has been organising when my scans are. I have not heard from the oncology department since finishing treatment.'*

AYA

## Palliative care Pūtau manaaki tūroro

Conveyed strongly in the work undertaken by the Network to date is the need for improved timeliness and early referral to palliative care services for young people and the current lack of age-appropriate and adequately resourced services for AYAs with cancer where curative therapy is no longer an option.

**32%** of young people currently undergoing treatment had not been given the opportunity to discuss what would happen if their treatment were unsuccessful and yet would have liked this opportunity

*'We are told Pete is dying, and has one to two days to live. The scan shows wide spread progression of the disease. How can this be all the warning we get? How can this be moral? We are asked if he would like to go to Hospice. He would know no-one; I am appalled it is asked. We have never even visited the hospice before.'*

AYA bereaved parent

*'I was a young girl preparing the real possibility of dying. I wanted to still have the opportunity to live life. There's 363 days in the year for the hospital to do as they please to generously contribute to my fight. And I only wanted the two days, so I gave them the better ratio right?'*

AYA

### ACTION STEPS

**Palliative care will be appropriately considered and provided by a skilled workforce**

Development of guidelines/pathways promoting early access to palliative care services when prognosis is guarded at diagnosis, when curative treatment cannot be offered, or if curative treatment is declined.

Development of AYA specific tools/resources to assist health providers, AYAs and their whānau in palliative care discussions and decision-making around palliative care needs and support.

Support the development and provision of an AYA specific palliative care education programme for those working with young people in either a palliative or cancer care capacity.

Establish an AYA cancer palliative care working group tasked with making further recommendations and providing expert oversight in this area.

**39%** of health professionals surveyed working with palliative AYA cancer patients around the utilisation of end of life documents in the AYA age group reported rarely or never utilising this resource with young people where curative treatment was no longer an option <sup>(16)</sup>



## Age appropriate information Pārongo hāngai ki ngā tau

AYA patients have both a right to and the desire for comprehensive, age-appropriate information to inform their decision-making and ensure they understand their treatment.

Currently there are limited or no centrally located, readily accessible, culturally appropriate AYA specific cancer resources.

Of those surveyed, over a quarter of young people felt information and resources provided to them were **not appropriate** for their age and level of understanding

### ACTION STEPS

**AYA will be provided with accessible, developmentally appropriate cancer related information**

Continue development of national AYA cancer resources and educational materials that can be accessed and understood by all AYAs while delivered across multiple platforms.

Expand and develop the AYA Cancer Network website to include a specific section tailored to the needs of young people through the inclusion of information, resources and relevant support contacts.

*'I chose to be more active in asking as many questions as possible and taking charge of my situation by being one step ahead at all times.'*

AYA

*'In my head I had lymphoma and not cancer because I failed to know they were both the same thing... So it was something I thought only needed a quick round of pills and voila I'll be good as new.'*

AYA



## Traditional and complementary therapy

### Haumanu inamata me te hāngai pū

It is becoming increasingly common for young people to use complementary therapies together with conventional cancer treatments.

Complementary therapies can help manage side-effects including pain, nausea and fatigue and improve the young person's wellbeing.

Traditional healing or Rōngōā Māori is an important part in the delivery of holistic care and wellbeing for many AYA undergoing cancer treatments. Value and importance must be placed on acknowledging, respecting, and exploring the safe use of traditional therapies when working with young people and their whānau.

**43%** of young people wished that they had received access to a complementary therapist for information and support around complementary therapy

#### ACTION STEPS

**AYA will be supported to safely explore or participate in the use of traditional and/or complementary therapies**

Develop recommendations and resources for AYA health providers regarding how to best support those young people and whānau choosing to explore or participate in the use of traditional and/or complementary therapies.

Develop educational tools and resources that support young people and their whānau choosing to explore traditional and complementary therapy options.

*'I think we should be able to openly discuss the benefits of the medicinal use of marijuana. It's not for everyone but I know many including myself that used this primary resource for pain relief and appetite. We should be talking about this more and not being afraid of it just because it's illegal.'*

AYA

*'My parents did some research about Māori medicine, they did some Chinese medicine, they did Indian medicine alongside of what I was doing in the hospital. They believe it went hand in hand...as well as the karakia and prayer.'*

AYA

*'We actually brought it in one time, my Nan actually brought it in... there was no acknowledgement towards it... we just wanted to be given a choice to try it out...'*

AYA

## Holistic wellbeing

### Oranga torowhānui

Low mood is an understandable and appropriate reaction to a cancer diagnosis, as is AYA patients thinking about and questioning the meaning and purpose of life. This type of thinking maybe described as philosophical, existential or spiritual.

Rates of significant depression and anxiety are consistently higher among AYAs in comparison to either children or adults diagnosed with cancer and their healthy peers. Poor psychological health in AYAs with cancer is associated with profound psychological suffering, impaired quality of life, and higher rates of non-adherent and risk-taking behaviours, which in turn contribute to poorer health and social outcomes<sup>(3)</sup>.

In the absence of clear psychological and spiritual screening, triaging and support pathways/guidelines, AYAs often receive variance in supports offered. Currently health professionals only have the option of applying adult-specific tools, and there is limited age-appropriate and effective resource and programme development.

Only **49%**  
of young people  
reported that they  
received support  
from a counsellor  
or psychologist

#### ACTION STEPS

AYAs will have access to psychological and wellness support from diagnosis

Support and promote the development of an array of wellness and supportive therapies that AYA may benefit from to assist with their healing and personal growth. These might include peer support programmes, spiritual counselling, music and art therapy, mindfulness and journaling workshops.

Develop formalised pathways and processes for identifying and treating psychological distress experienced by AYAs with cancer.

Develop resources to support the emotional wellbeing of young people throughout their cancer journey.

*‘Mental health support was frankly underwhelming – It was infrequent, short visits, with a different practitioner each time’*

AYA

*‘Finding peace with my new reality was a struggle. I had to accept the fact that I was unwell and breathe in my life’s new change, a change I never wanted. I had to accept the possible departure of the life I had built myself, the fact that things will never be the same’*

AYA

## Increased collaborative AYA cancer specific research Rangahau hāngai ki te mate pukupuku AYA pikinga ngātahi

Improved AYA cancer research is pivotal to attaining better long-term outcomes for AYAs with cancer.

Currently within New Zealand there is a lack of national oversight and cross sector awareness of AYA cancer research. A more collaborative approach to research is recommended to strengthen outcomes, encourage the cross-pollination of ideas and lead to better prioritisation and utilisation of scarce research resources.

*‘Why have we been able to equalise outcomes for 0-14 year old Pacific and Māori kids but not for AYAs?’*

AYA Cancer Consumer Advisory Group member

### ACTION STEPS

#### Adoption of a national, collaborative research approach

The Network is to provide national oversight and cross-sector awareness of AYA cancer research by:

- identifying priority areas of research in New Zealand for AYA cancer with a focus on the high level goal of reducing inequalities
- facilitating the development of a New Zealand specific AYA cancer research project directory
- supporting the dissemination of AYA cancer research
- facilitating opportunities to progress and undertake priority areas of research
- exploring opportunities for international collaboration on AYA cancer research
- supporting an increase in kaupapa Māori research, monitoring and evaluation.

## Age appropriate treatment environments Ngā wāhi pikinga o te ora kia ōrite ki ngā ta

It is essential that we treat AYA patients in an environment that provides developmentally appropriate care while facilitating access to age appropriate services and recreational resources.

In New Zealand dedicated AYA cancer treatment areas are not always feasible due to low numbers. However services can still achieve age-appropriate environments through simple measures such as co-locating AYA patients when possible, providing access to age appropriate recreational resources and information, and providing some flexibility in the structure of care.

**65%**  
of young people  
felt the environment  
they were treated  
in was always  
or often age-  
appropriate

### ACTION STEPS

**AYAs will be treated in health care environments that support and meet their developmental needs**

National guidance will be made available to providers outlining the principles of quality age-appropriate treatment environments.

Advocacy for a whānau based model of care within treatment environments.

The Network will support DHBs in the development and design of dedicated age-appropriate facilities within any new rebuilds or remodelling.

*'Being on an adult ward was terrible. I made it very clear I was going to be staying with my son and put him in a six bed room with five females. There was nowhere for me to sleep. Eventually they found a single room for us and gave me a LAY-Z-Boy to sleep in. But then they moved us out again. I was in tears trying to pack up all our stuff. They said I'd have to sleep on a couch in the corridor.'*

AYA parent

*'I was 16-17 surrounded by children under 10. I felt alone in my age group as I never saw someone my age and the environment is meant for younger kids but I don't mind.'*

AYA

# Concluding Remarks

## Ngā korero kua tau mai i tō mate

Since its establishment, the AYA Cancer Network Aotearoa has strived to create a national voice, representative of both the country's young people who have faced and will face a diagnosis of cancer, and the providers dedicated to improving these young people's lives.

The Network's voice is one of advocacy and a response to the knowledge that young people have unique and often unmet needs when compared to their child and adult counterparts.

The Network has spent recent years understanding these needs in detail to be able to develop and prioritise strategies that will empower our young people and the AYA cancer workforce to address the often stark inequities. Such strategies have now been presented in this national plan and it is hoped that the sector will continue their commitment, collaboration and drive to address survival and survivorship disparities for our young people, with our young people.

## THE VOICE OF THE YOUNG PERSON TE REO O TE TAIOHI



*I feel like I have had experience with every assistance available I've had support from Child Cancer Foundation, Cancer Society, Leukaemia and Blood Cancer Foundation, Make a Wish Foundation, Dove House, CanTeen, nurse specialists, nurses, doctors, Middlemore Hospital, Rotorua hospital, Auckland Hospital, medical specialists internationally (Australia and America) in corresponding calls with my Auckland care specialist and all those work alongside these great supporting networks.*

*I salute all my carers within and outside of the hospital for it is they that hold the cup of honour for my great news.'*

I am now in Remission and I am  
Esther Grace Pekepo.

Esther's cancer journey in full can be found on the AYA Cancer Network Aotearoa website and we encourage you to read it as it provides a heartfelt example of how working together can make the difference in a young person's life with cancer.



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This also includes each young person who has gifted their insight and experience and in particular, the AYA Cancer Consumer Advisory Group - **thank you**.

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*'I am proud to be part of a group who have been given a platform to have a say, to let our voices be heard not just for ourselves but for those who are no longer here. We want to be part of a generation that is going to make a change.'*

*AYA Cancer Consumer Advisory Group member*



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